

Virginia Dementia Specialized Supportive Services Project
Evidence-Informed Explanation for the Administration for Community Living

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The Effective Strategies Program (ESP) is an evidence-informed program modeled after the evidence-based Memory Club program and a very successful program implemented at the Hopital Fondation Sainte-Marie (HFSM) in Paris, France.

The Memory Club program involves persons with early-stage dementia and their caregivers in 10 to 13 sessions, typically lasting 90 to 120 minutes. Sessions are co-moderated by two leaders and involve expert speakers, such as neuropsychologists and social workers. Memory Club was designed to achieve five goals (Zarit et al., 2004; Gaugler et al., 2011).

1. Provide participants with information about symptoms, care options, community resources, and legal and financial issues.
2. Strengthen the relationship between the person with dementia and their caregiver by addressing communication and focusing on positive interactions.
3. Encourage the person with dementia and their caregiver to plan for the future, with an emphasis on long-term care and finances.
4. Participants are prompted to involve family and friends. They have the opportunity to invite them to a session and learn how to talk to them about dementia.
5. Persons with dementia and their caregiver have the opportunity to build relationships with other participants, which can provide support and a barrier against stress.

Each session focuses on a specific topic and is divided into three sections. Initially the person with dementia and their caregiver are together, they separate, and conclude the session by coming back together. This arrangement allows for group and individual concerns to be addressed, and the persons with dementia and their caregiver can interact with others experiencing the same situation. Topics covered by Memory Club sessions have included honoring identity, understanding the disease process, nutrition, exercise, safety, partnering with your doctor, participating in research, coping strategies, planning for the future, community resources, emotional and psychological reactions, communication, and role transformation (Zarit et al., 2004; Gaugler et al., 2011).

The following components of the ESP were adapted from the Memory Club program.

- Weekly sessions, which occur twice per week for 120 minutes (for a total of 20 sessions)
- Involves the person with dementia and their caregiver in the program
- Sessions are a mixture of bringing the person with dementia and their caregiver together, in addition to having opportunities for them to attend certain sessions separately
- Sessions are facilitated by experts including a neuropsychologist, social worker, physical therapist, nurse, neurologist, and speech therapist
- Provides a supportive environment for participants to build relationships and receive advice from experts by including time for socialization at the end of the session, which includes food
- Many of the same topics covered by the Memory Club program are included in the sessions and expanded upon using the success of the HFSM program

The HFSM program was created by combining evidence-based features of published research. The HFSM was designed taking into account research that supports the use of education and non-pharmacological strategies for individuals with Mild Cognitive Impairment and early-stage Alzheimer's disease (AD). As Director of the Memory and Aging Care Clinic at the University of Virginia researching methods to improve delivery of care to the residents of the Commonwealth of Virginia, I chose to spend three months at the HFSM because the curriculum is evidence-informed, it is successful in providing care, and they have rich years of experience. In addition, this is an ideal model to implement as care in the United States moves toward an accountable care organization model of care. Each component of the ESP is designed based on evidence-based literature. The review below describes relevant research, which is grouped by discipline.

Neuropsychology:

Research has demonstrated that individuals with mild cognitive impairment or early-stage dementia benefit from procedural memory training and learning new memory strategies (Clare, 2011; Rodakowski, Saghafi, Butters, & Skidmore, 2015; Zanetti et al., 2001). Individuals in the early stages of dementia often experience changes in their self-identity as a part of adjustment to illness and a recent study by Caddell and Clare (2011) suggested that the presence of coping strategies is a large factor in adjustment to dementia. Studies have demonstrated that patients with mild cognitive impairment and early dementia benefit from psychotherapeutic interventions (Regan & Varanelli, 2013). Group interventions, in particular, provide a feeling of being understood and accepted by others (Roberts & Silverio, 2009). This evidence-based research is incorporated into session 3 which includes information about memory and speech, while session 4 includes memory strategies. Session 7 will also be led by a neuropsychologist and will focus on adjustment to a diagnosis of dementia and discussion of self-identity.

Physical Therapy:

Authors of a recent paper reviewed 22 randomized control trials on the efficacy of physical exercise on cognition in individuals with mild cognitive impairment and dementia (Ohman, Savikko, Strandberg & Pitkala, 2014). Among the studies examining individuals with mild cognitive impairment, all but one study demonstrated positive effects of aerobic exercise on one or more domains of cognition, even in studies where the exercise program was for a short-duration (e.g., six weeks). A randomized control trial of exercise in individuals with amnesic mild cognitive impairment compared to an education control group indicated there was significant stability, if not improvement, in immediate memory and language among individuals in the exercise treatment group over the course of 12 months (Suzuki et al., 2012). Sessions 5, 10, 15, and 18 include an exercise program component facilitated by a physical therapist.

Occupational Therapy:

A randomized control trial indicated that community-based occupational therapy improves daily functioning of patients with dementia (Graff et al., 2006). Session 8 focuses on home safety. Gitlin et al. (2006) conducted a randomized study of safety interventions with community-dwelling older adults with functional limitations and found that increased education about home safety benefitted the participants in the treatment group, even at 12-month follow-up. Specifically, interventions that focus on modifying the environment and behavior of older adults significantly reduces the

number of hazards around the home, decreases fear of falling, and increases self-efficacy. Session 9 focuses on cooking exercises. Older adults with early-stage AD often face challenges to receiving proper nutrition, including increasing dependency on caregivers to prepare meals (Silva, Kergoat, & Shatenstein, 2013). Therefore, remaining independent in meal-preparation is important for older individuals. Session 16 includes community-based skill building and session 17 includes a shopping activity. Individuals with mild cognitive impairment often report difficulty remembering appointments, finding objects, and remembering items when shopping. An 8-week goal-oriented rehabilitation aimed at specific problem-solving skills significantly increased participant's ratings of their ability to perform these tasks (Londos et al., 2008). Similarly, a brief goal-oriented randomized control trial that addressed practical problem-solving skills and stress management for patients with early-stage AD over the course of 8 weeks found significant improvement in participant's ratings of their ability to perform tasks and their quality of life, even 6 months after the program ended (Clare et al., 2010).

Neurology:

Patients diagnosed with a memory-based disorder and their family members often ask about disease progression and treatments that will slow the progression. Seike and colleagues (2014) argued that education about the disease process and medical care should be a core feature of interdisciplinary interventions for early-stage dementia. Session 2 includes an educational session about dementia led by a neurologist.

Art Therapy:

Several case studies suggest that art therapy in individuals with Alzheimer's disease increases socialization, reduces neuropsychiatric symptoms, and increases self-esteem (Chancellor, Duncan, & Chatterjee, 2014). A multi-center randomized control trial comparing art therapy to general recreational activities in individuals with dementia suggests that art therapy is associated with greater sociability and improved mood (Rusted, Sheppard, & Waller, 2006). Session 14 includes an art-fusion style art therapy program focusing on art and emotions.

Nursing:

Older adults who have greater knowledge of healthcare and ability to access healthcare information have better decision-making skills (James et al., 2012). This suggests that an educational intervention may help older adults to have greater health literacy and decision-making skills. A recent study examining a health education course for individuals with early-stage dementia indicated that not only were individuals with memory impairment able to learn the information presented, but those in the treatment group had significantly higher amounts of exercise, socialization, and greater changes in health habits when compared to a control group (Buettner & Fitzsimmons, 2009). Furthermore, individuals with early-stage dementia who participate in health promotion classes have higher ratings of self-efficacy and are more willing to engage in future care planning than control groups (Richeson, Boyne, & Brady, 2007). Session 13 includes information about managing health.

Social Work:

Higher levels of financial knowledge and literacy are associated with better decision-making among older adults (James et al., 2012); therefore educational programs aimed at increasing financial

literacy in individuals with dementia may impact responsiveness to discussions about future financial planning (Hsu & Willis, 2013). Individuals with mild cognitive impairment often experience deficits in their awareness of difficulty managing finances (Okunkwo et al., 2008; Van Wieringen et al., 2004). Tappen and colleagues (2014) demonstrated that practical skill training, such as making change and balancing a checkbook, can increase independence in these skills among individuals with early-stage AD, particularly with tasks such as shopping. Furthermore, clinical case management for individuals with early-stage AD significantly reduces caregiver burden and delays institutionalization when compared to a control group (Chu, Edwards, Levin, & Thomson, 2000). Consistent with this research, session 6 includes information about financial resources and practical matters.

Speech Therapy:

There is evidence to suggest the development of language deficits in early stages of the disease process (Goldfein, 2007). Research has demonstrated that language exercises and socialization are associated with slower rates of decline among individuals with mild-to-moderate AD (Arkin, 2007); therefore the incorporation of speech language pathologists in multidisciplinary dementia programs is strongly recommended (Goldfein, 2007). The sessions with the speech therapist (sessions 11 and 12) focus on language exercises associated with slower rates of decline.

Conclusion

As noted above, there is strong evidence that non-pharmacological strategies, such as the Memory Club program and the HFSM program, provide benefits to persons with dementia and their caregivers. Strong evidence for institution delay has been found for multi-component interventions, along with reproducible evidence for improvements in activities of daily living, behavior, mood, and cognition (Olazarin et al, Dementia and Geriatric Cognitive Disorders, 2010). While improvement in abilities would be a highly desirable outcome, delay of institutionalization alone would bring significant cost savings to the Commonwealth of Virginia. Furthermore, maintaining, rather than improving abilities in light of neurodegenerative disease would be a positive outcome. Interventions utilizing cognitive stimulation, such as in the proposed ESP program, have found cognitive benefits for people with mild dementia (Woods et al., Cochrane Database, 2012). As such, the evidence-based, multi-component structure of the ESP will capitalize on benefits to our constituents and provide state-of-the art care to individuals with dementia in the Commonwealth of Virginia.

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